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DATE: October 19, 2004

TO: INTERESTED PARTIES

SUBJECT: BIANNUAL MORTALITY STUDY

Enclosed for your information is "California DDS Biannual Summary of Community-Based Mortality For Data January-June 2002". This report was produced by The Columbus Organization (TCO) in collaboration with the Department of Developmental Services (DDS). DDS has contracted with TCO for numerous risk management services. One contract requirement is a biannual report on mortality of consumers living in community settings. This format represents the routine analysis and reporting of mortality data for trends, outliers and noteworthy data events.

This report shows community-based client mortality by regional center, residence type, week to week comparisons, and also the number of deaths in which the causes were able to be determined as well as the number of deaths with undetermined causes.

The report concludes that the described mortality rates and patterns, when compared to other states and similar populations, fit expected rates and patterns of mortality for a large population of people with developmental disabilities. Regardless of this conclusion, DDS continues to focus on and devote resources to access for quality health care for consumers living in the community. DDS utilizes the Special Incident Reporting (SIR) System to gather valuable information regarding the services consumers receive and consumer outcomes.

DDS continues to pursue improvements as a result of many sources of data, including the enclosed study. Strong emphasis is currently focused on health promotion, screening tests, and increased quality management and accountability systems of health care services. In addition, DDS continues to support the Wellness Initiative and collaborative partnerships to promote quality health care services for all Californians with developmental disabilities.

Please contact Jo Ellen Fletcher, Chief of DDS's Health and Wellness Section, at (916) 654-2133 if you have any questions regarding this study.

Cordially,

***Original Signed By***
CLIFF ALLENBY
Director

Enclosure

# California DDS
# Biannual Summary of Community-Based Mortality
# For Data January-June 2002

## Presented by
## The Columbus Organization

## Biannual Summary of Community-Based Client Mortality, CA DDS 2002

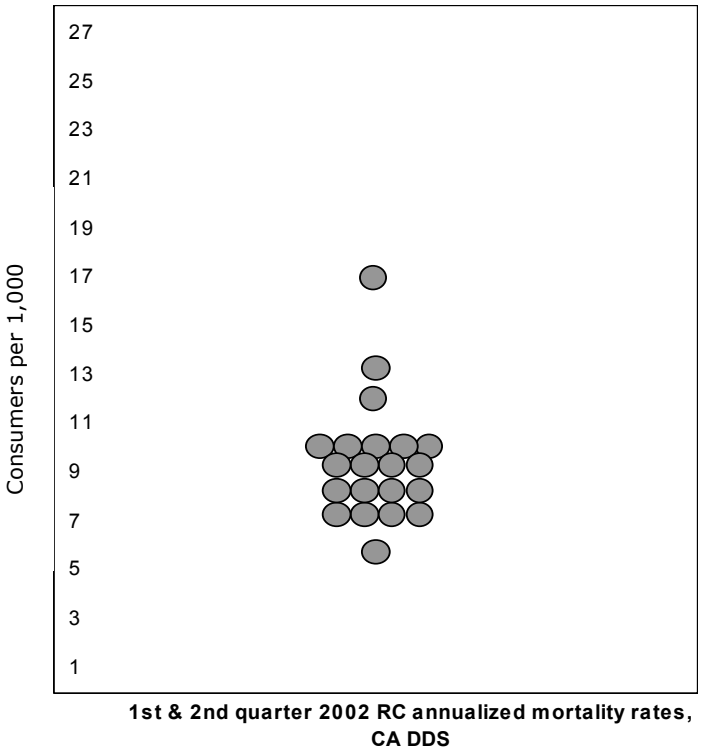
The population of interest includes 148,423 California Department of Developmental Services (DDS) consumers living in the community and receiving services. This data was obtained from the California DDS Quarterly Client Characteristics Report Index (QCCRI). Thus, the source of all denominator data for rate computation was the QCCRI. The client deaths, as reported through the Special Incident Reporting System (S.I.R.S.), have been counted and then divided by the base population in order to calculate the rate of death per 1,000 clients. Furthermore, all rates continue to be adjusted to an annual rate by extrapolating the quarterly or semiannual rate out to one full year. These are crude rates - meaning the rates are not adjusted across regional centers, residential types, or any other factor to enable more balanced comparison. The variation among regional centers will likely diminish as we accrue more months of data since the effect of small numbers (months) is less over time.

## Highlights and Summary

The accuracy and reliability of S.I.R.S. reports of death appears to be good as the measures fit expected rates and patterns for a large population of people with developmental disabilities. The first six months of information reveals anticipated seasonal variation. The magnitude and chronological peak of this past year's influenza season fit with trends in the CA DDS measures. The differences in crude rates among populations by residential type were not surprising. Finally, comparisons with mortality rates from other states indicate substantial similarities. There is a rather narrow variation in rates across regional centers within the State of California.

Again, reporting of client deaths appears to be complete and timely through the S.I.R.S. If there are any delays in reporting, it is seen within the residential type subpopulation of clients residing with a parent/guardian.

*Figure 1 (below) A distribution graph of the annualized mortality rate for all regional centers for the first half of 2002. One can see at a glance that the median rate for all regional centers is about 9 per 1,000 per year, while the range is about 5 to 17. This graphical method of depicting measures of central tendency and spread is particularly useful for a large number of data points. The y axis is simply the annualized mortality rate per 1,000 clients. Note that there is no x axis.*



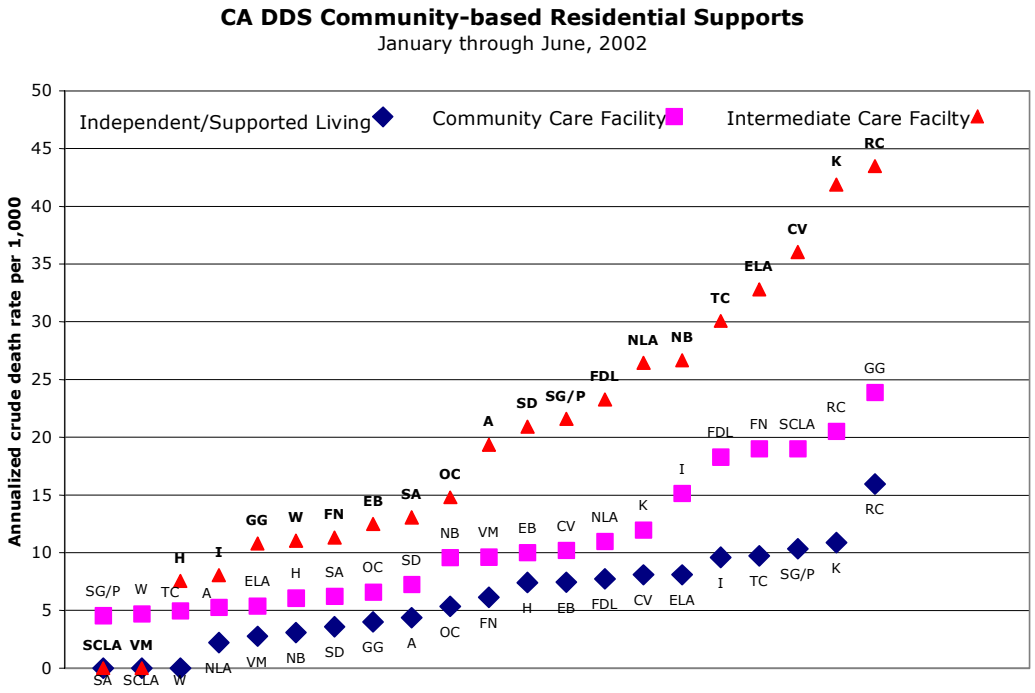
There was little change in the quarter-to-quarter proportions of client deaths among residential types. Community care facilities (4 – 6 beds) and skilled nursing facilities/nursing facilities (SNF/NF) accounted for more than one-quarter of all client deaths. Overall, there were 685 deaths statewide for this time period.

*Table1 Breakdown of rates by residential category. (Midpoint census on April 4, 2002)*

| Residence type | Mid-point census | Deaths | Annual rate /1,000 |
|---|---|---|---|
| Parent/guardian home | 100,748 | 324 | 6.43 |
| Independent living | 14,733 | 45 | 6.11 |
| Community care facility | 21,085 | 109 | 10.34 |
| Intermediate care facility | 7,027 | 67 | 19.07 |
| SNF / NF | 1,394 | 109 | 156.38 |
| Other | 3,436 | 31 | 18.04 |
| **Aggregate total** | **148,423** | **685** | **9.23** |

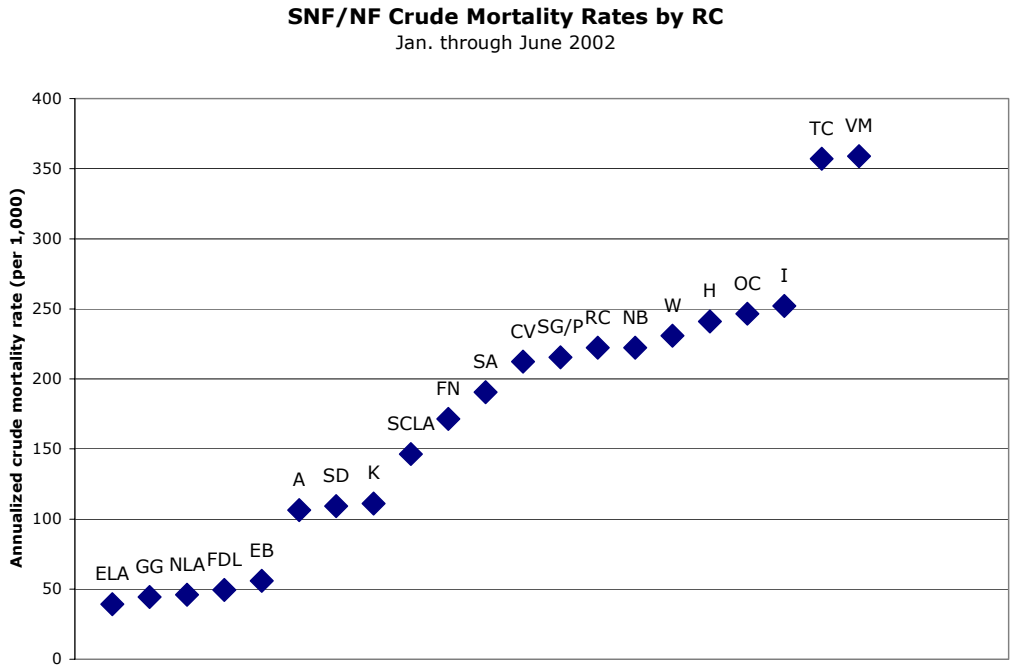
The variation among regional centers reveals a fairly tight spread for residential types, independent/supported living and community care facilities. There was notable variation among regional centers in the annualized mortality rate for the residential type intermediate care facility – with a range of about 7 per 1,000 per year to more than 42 per 1,000 per year, yielding an annualized rate of 9.23 per 1000, as illustrated in the graph below.

*Figure 2- Distribution graphs of Jan – Jun 2002 Mortality: Independent/Supported Living, Community Care Facility, Intermediate Care Facility*



The spread among regional centers for skilled nursing facilities/nursing facilities (SNF/NF) was less than 50 per 1,000 per year to more than 350 client deaths per 1,000 per year. These annualized rates for the first half of 2002 are represented by simple graphs with the regional center rates sorted from low to high. While the SNF/NF mortality is high in comparison to other residential settings, it is understood that the healthcare needs are much greater in this relatively small subgroup. The SNF/NF subpopulation also represents less than 1% of the community-based population, so the effect of small numbers may interfere with reasonable comparison among residential types.

*Figure 3 - Distribution graphs of Jan – Jun 2002 Mortality: SNF/NF*



The weekly variation in client deaths is represented in the following Statistical Process Control (SPC) chart shown below. This analysis of variation over time does NOT include the community population of clients living with a parent/guardian because of the effect that reporting delay has on the latest weeks of the period of interest. In this form of analysis, the upper limit, beyond which significant counts would have occurred, were not crossed during the six-month interval. There were also no instances of consecutive weeks with upward or downward trends. The chart is split mid-year to reflect the real seasonal variation that is seen in mortality. Finally, there were no consecutive weeks where the count remained above or below the center line (average) for more than six weeks. All of these examples would have signaled a special situation acting within the system (i.e., an epidemic or a moderate to severe influenza season).

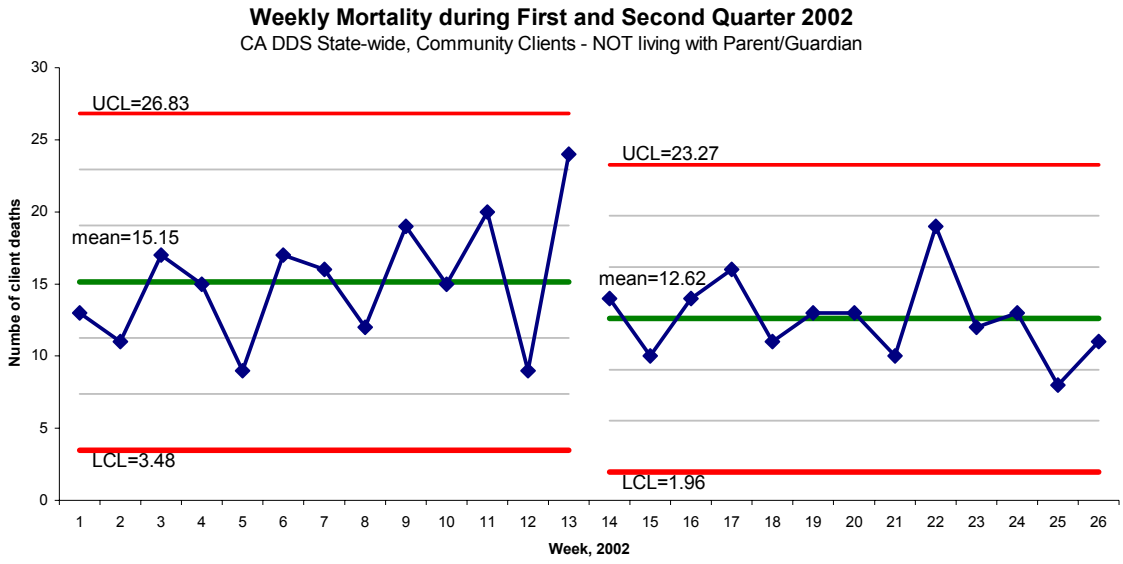



*Figure 4 SPC chart of weekly client death counts*

The third quarter counts should continue to decrease until Fall of 2002 when the seasonal variation will reveal an increase into the Winter. Over time, the ability to set upper control limits by season or quarter will allow stakeholders to anticipate death counts that require immediate action. The upper control limit (UCL) for the first quarter alone was 26.8 client deaths per week. The UCL for the same interval

minus the last week of data was 25.8 deaths per week. Finally, calculation of UCL for the second quarter only was 23.3 client deaths per week.

## Undetermined Cause of Death Assignment from S.I.R.S.

More than one-third of the reports of client death in the Special Incident Reporting System contain insufficient information for analyzing presumptive cause of death. The narrative fields within the S.I.R.S. record are used to glean pertinent clinical information for this analysis. This presumptive assignment of cause of death is also independent of the death certificate because that information is often not available at the time of the S.I.R.S. report and because this information is typically inaccurate unless completed by a pathologist. This proportion of undetermined cause of death did decrease from first to second quarter, however, there is no good benchmark information available to anticipate the expected rate of undetermined cause of death within a community-based system of support. It is unreasonable to ever anticipate a proportion of zero percent undetermined cause of death for any time interval. Even in series where all decedents are examined by *autopsy*, there have been reports of classification “undetermined” or “unknown” as high as ten percent. In our experience, CA DDS’ rates of undetermined cause of death approximate those in other states where we have examined this issue, including Oklahoma, Louisiana and Tennessee.

Some form of pneumonitis due to infection or aspiration or a chronic restrictive pulmonary disease appeared to be responsible for the next largest proportion of client deaths, behind undetermined. This is very consistent with population measures in other systems. Other important causes of death were probable myocardial infarction (heart attack) and some form of cancer. Nearly all of the clients with cancer had the primary cancer identified and were receiving care for their terminal disease. The rate of injury fatality is very low for this population, as one would expect for a chronic care population with general supervision.

*Figures 5 and 6 Charts of first and second quarter "undetermined cause of death" by RC*